

# The Associations of Chronic Condition Type and Individual Characteristics With Transition Readiness

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## ABSTRACT

**OBJECTIVE:** Identifying differences in transition readiness according to chronic condition is essential for understanding whether special emphasis within specific populations is warranted. Youth with chronic conditions (type 1 diabetes, Turner syndrome, spina bifida, autism spectrum disorder [ASD]) representing various types of impairments were compared with youth without chronic conditions. It was hypothesized that differences would be observed according to condition type, with youth with cognitive/behavioral conditions showing less readiness than youth with other conditions and youth without chronic conditions showing the highest levels of transition readiness.

**METHODS:** Patients (N = 163) ages 12 to 22 were recruited via outpatient clinics at a large freestanding children's hospital. Demographic characteristics (age, sex, race, and maternal education), health literacy, perceptions about health care responsibility, importance and confidence about transfer to adult health care, and the Transition Readiness Assessment Questionnaire (TRAQ) were included.

**RESULTS:** Significant differences in transition readiness were found according to condition type; youth with ASD had the lowest transition readiness scores. Patient and family characteristics and condition were predictors of TRAQ scores and self-perceived readiness to take responsibility for health care and transfer to adult care. Item-level analysis indicated that medication, appointment-keeping, and activities of daily living accounted for differences in TRAQ scores according to condition.

**CONCLUSIONS:** Disparities in transition readiness were detected across condition types, with potentially modifiable mechanisms identified to address gaps in readiness for youth transferring to adult health care systems. Developing interventions that assist providers in addressing these modifiable characteristics might improve transition to adult health care for adolescents with various chronic conditions.

**KEYWORDS:** adolescent; chronic conditions; health care transition; transition readiness; young adult

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## WHAT'S NEW

This study is among the first to identify variation in readiness among youth with differing types of chronic conditions preparing for adult health care. Findings suggest the importance of tailoring approaches to health care transition for youth with medical, cognitive, and behavioral impairments. Such an approach might address these disparities.

ADOLESCENCE REPRESENTS A period of increased vulnerability,<sup>1</sup> when many lifelong health habits are established,<sup>2</sup> health care utilization rates begin to decline,<sup>3</sup> health management duties move from parent to child,<sup>4</sup> and transfer from pediatric to adult health care providers commonly occurs.<sup>5</sup> The literature on pediatric to adult health care transition (HCT), characterized by a change

from a pediatric to an adult-oriented health care system and shifts in disease management for youth with chronic conditions, has further highlighted this vulnerability.<sup>6,7</sup> Competing developmental tasks (eg, education) often take priority over health care, which is particularly concerning for adolescents and young adults (AYA) with chronic conditions.<sup>8</sup>

Researchers have recently focused on evaluating HCT and factors that contribute to AYA being prepared to manage their health care. Validated measures of HCT readiness have been used with heterogeneous samples of youth with chronic conditions,<sup>9</sup> with specific chronic conditions,<sup>10–14</sup> and in youth without chronic conditions.<sup>14</sup> Most theories about HCT for AYA have emphasized transition readiness across chronic conditions.<sup>15,16</sup> These theories have emphasized that individual and contextual characteristics; AYA skills, beliefs, and knowledge; and parents, providers, and the health care system all

contribute to successful HCT. In contrast, empirical work done in clinical populations has emphasized transition readiness measured according to knowledge or self-reported management of particular health tasks (eg, refilling prescriptions) within specific chronic conditions.<sup>13,17</sup> It is unclear whether there are systematic differences in transition readiness among AYA with varying types of chronic conditions.

The competing hypotheses that HCT could be a challenge related to either general factors experienced by all AYA or unique among AYA with specific chronic conditions reflects theoretical work in self-management (an element of HCT) and social functioning.<sup>4,18</sup> To date, few HCT studies have intentionally compared aspects of transition readiness in AYA across categories of chronic conditions. Identifying differences (if they are present) among AYA with particular types of chronic conditions is important to develop and target interventions to increase transition readiness. For example, chronic conditions could differentially affect transition readiness because of the timing of the onset of a condition; the physical, emotional, and cognitive manifestation of a condition; and how that condition is managed and affects the family.<sup>19,20</sup>

To better understand the effect of chronic conditions on HCT readiness, this study examines HCT readiness in 5 groups of AYA: type 1 diabetes, Turner syndrome (TS), autism spectrum disorder (ASD), spina bifida, and AYA without any chronic conditions. These populations were selected to provide a spectrum of medical, behavioral, and cognitive considerations, and because there were stakeholders invested in doing HCT research working with those populations. AYA without any chronic conditions represented youth without medical, behavioral, or cognitive effect. Type 1 diabetes represented youth with a chronic medical condition without behavioral or cognitive effect. TS represented youth with medical and cognitive but not behavioral effect. ASD represented youth with behavioral and cognitive but not medical effect. Spina bifida represented youth with medical and cognitive but not behavioral effect. We hypothesized that HCT readiness would differ according to condition, with AYA without any chronic conditions to have the highest indicators of transition readiness. We further expected that AYA with developmental disabilities (ie, spina bifida and ASD) and neuro/sociocognitive deficits (eg, TS, spina bifida, ASD) would have lower indicators of readiness because of the communicative and cognitive effects of those conditions on adolescent functioning.<sup>10,11,21</sup> We expected lower HCT readiness to manifest itself in specific domains of functioning related to known deficits for particular chronic conditions. Finally, in line with theoretical models of HCT, we anticipated that sociodemographic characteristics would predict HCT readiness.

## METHODS

### PARTICIPANTS

AYA (N = 163) ages 12 to 22 years were recruited. AYA were from 1 of 5 populations: 1) youth with type 1 diabetes

(n = 35), 2) youth with TS (n = 35), 3) youth with ASD (n = 35), 4) youth with spina bifida (n = 23), and 5) youth without any chronic conditions (n = 35). Recruitment goals (n = 35) were met for all groups except spina bifida within 12 months; after 12 months, recruitment was stopped for spina bifida.

### PROCEDURES

Research staff identified potentially eligible participants through patient registries and outpatient clinic appointments scheduled in type 1 diabetes, TS, spina bifida, and ASD clinics as well as through the Teen Health Center. Potentially eligible patients were approached during clinic visits, or families received letters describing the study and informing them that study staff might approach young people during upcoming visits. For youth with chronic conditions, eligible AYA were: 1) between the ages of 12 and 22 years, 2) able to answer questions independently, 3) English speaking, 4) reading at or above the third grade level with intelligent quotients >85, and 5) without comorbidities not related to their primary diagnosis. For youth without chronic conditions, the same eligibility criteria was applicable, and in addition youth completed the eligibility screener from the 2009/2010 National Survey of Children with Special Healthcare Needs<sup>22</sup> to ensure that they did not have a chronic condition. The study received institutional review board approval. Participants aged 18 to 22 years provided consent to participate. For participants younger than 18 years, parents provided consent and participants provided assent to participate. Participants received surveys at clinic appointments and either completed surveys during the clinic visit or at home and returned them by mail. For AYA with type 1 diabetes, TS, ASD, and without chronic conditions, all youth meeting eligibility criteria agreed to participate. For spina bifida, 71 participants were notified about the study either by letter or during clinical encounters and 23 participated, with a recruitment rate of 32%. Participants received a \$15 gift card for participating in the study.

### MEASURES

The primary measure of “transition readiness” was the Transition Readiness Assessment Questionnaire 5.0 (TRAQ), a 20-item validated measure that is used to examine knowledge and self-reported health-related skills.<sup>9</sup> TRAQ has been previously tested and validated with 461 youth ages 16 to 26 years across 2 studies and 3 diagnostic categories: activity-limiting physical conditions (eg, type 1 diabetes, spina bifida), cognitive impairment (eg, ASD, TS), and mental health (eg, attention deficit hyperactivity disorder, learning disabilities; groups not represented in the current study). The TRAQ addresses appointment-keeping, tracking health issues, managing medications, talking with providers, and managing daily activities. Item responses are on a 5-point Likert type scale ranging from 1 (no, I don’t know how) to 5 (yes, I always do this when I need to). Responses across items are averaged to determine a total score ranging from 1 to 5 (sample

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